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## **Abstract**

**Aims:** At first episode psychosis (FEP) many patients will be routed within familial networks and supported by informal carers who are predominately close family members such as parents. Carer burden, distress and poorer coping styles are associated with different illness beliefs. The current study sought to examine the impact and acceptability of a three session, cognitively informed, group intervention targeting illness beliefs previously linked to distress and poorer caregiving experiences in FEP carers.

**Methods:** Carers attending a routine FEP service were invited to attend the group intervention and completed a measure of illness beliefs at baseline and post intervention.

**Results:** Data on 68 carers with complete datasets are presented. Carers were predominately female (64.2%). Group attendance was linked to positive improvements in carer baseline beliefs about the negative consequences of the illness for the patient and themselves, attributions of blame about the illness to the patient and themselves, and their overall understanding about the illness. Significant improvements in their understanding of the illness timeline and course, and confidence in dealing with difficulties were also identified.

**Conclusions:** A cognitively informed group approach to targeting the less adaptive illness beliefs reported by FEP carers may offer an effective and acceptable pathway to facilitating their understanding of the illness and adjustment. Further studies using controlled designs are required.

## **Background**

High levels of isolation are reported by people with psychosis.<sup>1</sup> Families play an important role in supporting the care and treatment of individuals with psychosis, which is a picture particularly evident following the first onset. Carers are often instrumental in organising access to and receipt of mental health service at onset<sup>2</sup> and responding to incipient signs of relapse and crisis.<sup>3</sup> Recent evidence links their involvement to improved mortality rates<sup>4</sup> including for first onset patients.<sup>5</sup> However, the caregiving role can have a negative impact on carer health and this has been extensively documented over the last few decades but with a more recent focus on the needs of early psychosis carers.<sup>6-8</sup>

Psychosis in a family member can be associated with high levels of stigma and shame<sup>9-10</sup> and feelings of desperation.<sup>11</sup> Social isolation in carers is high with recent evidence suggesting they were 10 times more isolated than non-carers.<sup>12</sup> The caregiving role is commonly linked to high levels of burden, stress and distress<sup>8</sup> which is significantly higher in early psychosis populations<sup>13-14</sup> and can persist over the illness course.<sup>15-16</sup> Approximately 40% of early psychosis carers report depression and anxiety<sup>17</sup> and in a recent review of a routine clinical early psychosis sample, clinical markers of ‘burnout’ were recorded in 78% of the sample.<sup>18</sup> Reports of sleeping difficulties are significantly higher in psychosis carers compared to carers of people with other conditions (e.g. cancer, dementia, stroke).<sup>7</sup> High levels of loss and grief have been recorded in early psychosis carers, which are indistinguishable from bereavement reactions following a death.<sup>19</sup>

### Carer illness beliefs

Given their contribution to patient outcomes and the negative impact of caregiving, there are increasing efforts to improve our understanding of carer reactions at first episode with the aim of identifying pathways to promoting and supporting adaptive coping responses. Much of

this work has focused on identifying the illness appraisals (i.e. beliefs) reported by carers and exploring links to carer functioning, including how they respond to illness symptoms and cope.<sup>20-22</sup> We know that carers with less adaptive coping styles report higher levels of distress.<sup>23</sup> In FEP populations, the evidence suggests that carers' perceptions about the negative and severe consequences from the illness and illness chronicity are positively linked to greater levels of distress.<sup>24-25</sup> A greater focus on interventions targeting carer illness beliefs as a potential pathway to reduce carer distress is increasingly indicated.

Interventions specifically designed for carers are recommended in recent treatment guidelines for psychosis conditions<sup>26</sup> and can impact on psychological distress and key outcome indicators.<sup>27-29</sup> Though we lack a definitive model to account for the different beliefs that carers report, we do know for example that higher levels of carer distress are linked to illness beliefs reflecting greater illness consequences, a longer illness duration, and a perception of having no control over the illness and outcomes. It is possible that supporting carers to develop illness beliefs and a conceptual model that is informed by current available evidence and good practice, and devoid of myths and self-blaming attributions, would be beneficial at any stage but particularly soon after first episode.

Previous research evaluating interventions to modify carer illness beliefs have generated encouraging findings.<sup>30-31</sup> Petrakis et al<sup>30</sup> delivered a 5 week group psychoeducation programme for FEP carers. Though the sample was small (n = 8-11), the findings at post intervention indicated significant increases to carers' understanding about psychosis, recovery, and relapse prevention. Using a larger sample (N=18), Lowenstein et al<sup>32</sup> evaluated a pilot 12 session, 6 month cognitive group with FEP carers. The group programme covered a number of topic areas which included information on understanding psychosis and treatments. Post group analyses revealed significant decreases in carer reports of burden and depression. A qualitative investigation of twelve FEP carers' attendance at an 8 week

education group highlighted a positive impact on their reported understanding of psychosis, levels of confidence, and reductions in self-blame attributions.<sup>31</sup> To date, most published FEP intervention studies have incorporated longer interventions (6 or more sessions) that have also been undertaken with relatively homogenous samples in terms of reported ethnic background. Evaluating the impact with more diverse samples is an important consideration in areas such as the United Kingdom where there remains a higher incidence of diagnosed psychotic disorders in some black and minority ethnic groups (BAME).<sup>33-35</sup> Further, the meanings assigned to illness symptoms and labels can differ between and within carer and patient groups, depending on ethnic membership.<sup>36-38</sup> Qualitative investigations of BAME service users and carers accessing early intervention in psychosis services suggests an increased need for better information about illness course and recovery outcomes.<sup>39</sup>

### *Study aim*

The current study sought to examine whether a brief (3 session) group intervention, which included a cognitive focus designed to specifically target key illness beliefs previously linked to carer distress and negative caregiving experiences, could positively impact on negative illness appraisals in FEP carers. We hypothesised that carer participation with the group psychoeducation programme would be associated with improved models of illness as reflected by reductions in the perceived negative consequences of the illness and blame attributions. Improvements in overall understanding of the illness particularly with regard to the timeline and treatments were also hypothesised. No hypotheses were offered concerning beliefs about patient and carer control as it was unclear what changes would represent an improvement at this stage of the illness phase.

## **Method**

### **Design**

A cross-sectional design using pre post measures was employed. The sample was the identified carers of service users under the care of an Early Intervention in Psychosis Service in the Central and North West London NHS Foundation Trust. The service accepts referrals for FEP cases in the local area and delivers services to an estimated 180 carers at any one time. Patients are eligible for the service if aged 14-34 years, with a duration of untreated psychosis of less than 12 months. Combinations of best practice pharmacological, psychosocial and vocational interventions are provided as part of an assertive outreach service model. The collection of routine service data were carried out in accordance within the Trust protocol for governance for service research, evaluation, audit and includes participants' informed consent to publish.

### **Intervention**

The psychoeducational group comprised three 2 hour group workshops held over three consecutive weeks. Given the mental health costs<sup>40</sup>, if a smaller number of sessions were able to yield favourable outcomes for carers, there may be an increased likelihood of future uptake by service providers and carers. The content was cognitively focused and embedded within a bio-psycho-social framework of understanding the onset, maintenance and relapse of psychotic disorders. Session 1 focused on improving understanding of psychosis conditions in terms of symptoms, causes, course, timelines, impact and treatments. Session 2 focused on caregiving experiences and carer needs, including optimising adaptive coping strategies. Session 3 focused on different approaches to caregiving and targeting specific problems. All

sessions followed a similar structure, which included a session agenda, opportunities for peer-to-peer discussion, homework assignments and drawing links between beliefs, affect and behaviours particularly as they related to adaptive coping strategies. The workshops were held at a Trust site and were facilitated by a consultant psychiatrist and clinical psychologist from the psychosis team. Session content was delivered through PowerPoint presentations and facilitated group discussion. Group members were given handouts from the workshops.

## **Procedure**

All known carers to the team were invited to attend.

## **Measures**

The assessments were administered by the team assistant psychologist. Participants completed a self-report, purposively designed, questionnaire that included a list of 10 illness belief statements that were based on items from Broadbent et al <sup>41</sup> and Lobban et al <sup>21</sup> adapted illness belief questionnaires. Participants were required to read through a series of statements and indicate the degree to which they agreed with the statement on a visual analogue scale anchored from 0 to 100%. e.g. *How much control do you think your relative has over their illness? How much do you think you are to blame for your relative's illness?* Higher scores on each item indicated stronger endorsement of that belief.

## **Analysis**

All data were analysed using SPSS for Windows Version. <sup>42</sup> Descriptive statistics were used to present demographic data. Paired-sample t tests were used to assess the differences between baseline and end of intervention illness beliefs scores.

## **Results**

One-hundred and forty-nine carers attended who were caring for 100 patients. Two carers (2/149) refused permission to publish and therefore do not appear in any reported analysis. Of the 147 carers involved in the analysis, 68 carers (45%) provided complete before and after data, with informed consent to publish, and were caring for 48 (54%) of the patients. The 68 carers who gave complete outcome data were compared to the carers who did not (n=79). No significant differences were observed between the two carer samples on gender or relationship to patient but the full outcome group were slightly older (52 years vs. 48 years) and there were fewer carers of Asian ethnicity (25% vs 41%). No differences were found between the service users in both groups.

In the final sample of 68 carers, the mean number of sessions attended was 2.76 (SD. 042) with more than two thirds 75% (n= 51) attending all sessions. The majority of participants were female (64.2%, n=43) and carers' overall mean age was 52.6 years (SD = 11.6; Range 17-70). In terms of ethnic background, two thirds of carers were white British (65.7%, N=44). The remainder of the sample were Asian (25.4%, n=17); Black (7.5%, n=5), and Mixed/other (1.5%, n=1). Most were the parents of the identified service user (92.5%).

In terms of patient data, two thirds were male (66.7%), with a mean age of 22.8 years (SD = 5.50, Range 12-35). The mean length of psychosis illness, as calculated from clinical notes, was 1.78 years (SD= 1.34 years, range = 35 days -7.72 years).



### *Belief change*

Table 1 reports the pattern of belief change following group attendance in the 10 key beliefs measured. There were significant ( $P < 0.01$ ) positive shifts in carers' beliefs about the perceived consequences of the illness for the patient, attributions of blame towards their relative and themselves, and overall understanding of the illness (coherence). There were also significant positive shifts ( $P < 0.05$ ) in carers' beliefs about the negative consequences of the illness for themselves, the timeline of the illness, the degree of control patients have over their illness, and amenability of the illness to treatments. Carers' confidence in dealing with difficulties showed a significant positive increase.

No significant changes were observed in carer beliefs in about the amount of control they have over the illness.

### **Discussion**

The study sought to assess whether a brief cognitive based intervention could impact on key illness beliefs reported by FEP carers in a routine service. The results suggested that cognitive models of illness reported by FEP carers appear to be malleable following a relatively very brief intervention. In line with previous literature,<sup>18</sup> baseline scores indicated that carers endorsed a range of negative illness beliefs. It is perhaps unsurprising that many carers presented as being unclear or lacking an understanding about psychosis. The mean length of psychosis illness was approximately 17 months and therefore many carers are likely to have been dealing with the shock of the episode occurring and their relative's entry into services, which may have interfered with or compounded opportunities to increase their understanding of the illness experiences.<sup>8-9</sup> Blame attributions were present with at least 25%

of the sample apportioning blame for illness aetiology to themselves and/or patients. Carer distress has been positively associated with and predicted by reports of self-blame.<sup>22, 43-44</sup> Moreover, self-blame underpins carer reactions characterised by intrusiveness and emotional over involvement,<sup>45</sup> which in turn have been linked to higher levels of relapse and readmissions in patients<sup>46</sup> and poorer carer functioning.<sup>47</sup> In line with hypotheses, carers developed a less negative understanding of the illness that was reflected by significant decreases in their perception of the negative consequences of the illness for the patient and themselves, and the degree to which they held themselves and their relative blame worthy. It was also noted that carers' appraisal about their overall understanding (coherence) of what psychosis conditions are, optimism over their amenability to treatments and perhaps, more importantly, the degree of confidence in themselves about being able to cope was also positively impacted by the group. We put forward no predictions about how the group would relate to carer beliefs about illness control. The results offered no significant differences to carers' beliefs about the amount of control they have; however, their beliefs about how much control their relative had significantly increased. It is possible improvements in beliefs about patient control reflected reduced hopelessness about the impact and effects of the illness (i.e. negative consequences) and a better understanding about the illness as a whole and treatments.

Carers' reported understanding about the illness course changed thus indicating an improved understanding of the fluctuating and episodic nature of the conditions. This would seem an important progression since FEP carers can report confusion about the illness and experience significant distress after a relapse. For those working in early intervention services, it can be a delicate balancing act trying to establish and maintain therapeutic optimism whilst also being cognizant of individual vulnerabilities and the strong potential for relapse in the future.

Carers reported high levels of satisfaction with the service intervention with more than 90% reporting they would recommend it to others. It is possible that where carers are offered opportunities that allow them to make sense of the illness with peers, within evidence based, supportive frameworks, positive shifts in their beliefs about the illness consequences and illness blame can follow.

A number of clinical implications are presented by the current findings. If the intervention proves effective in different settings, it is possible that a highly focused but simple and easily delivered intervention could be integrated in a routine service with minimal economic investment. The potential to reach large numbers of carers in one sitting, and support their understanding and adaptive responses to psychosis, may also improve clinician attempts to engage and work effectively with patients and improve their overall outcomes. Carers' positive impact and important influence on patient engagement in psychosis services has been noted in the literature.<sup>2</sup> Consequently, engaging with carers in a positive manner and on issues of importance in their day-to-day functioning may positively impact also on patient engagement styles. As reported earlier, carer distress peaks during the early illness phase and more so, when combined with an admission.<sup>14</sup> Helping carers in their attempts to make sense of what is a life changing event for their relative and themselves, and to reduce their distress levels, may be partly supported by ensuring they have an adaptive model of illness. It would be one that is free of blame attributions for themselves and their relative, and optimises beliefs about hope or room for development and progression. A further implication reflects the importance of supporting carers to learn more and extend their understanding about psychosis, but within a group setting and with similar others. As discussed, the experience of psychosis can be extremely isolating for carers;<sup>12</sup> facilitating opportunities for families to get together may help to reduce appraisals of isolation and help destigmatise the experience of

psychosis.<sup>11</sup> Finally, routinely assessing carers about their illness beliefs on entry to early intervention services should help to prioritise carers in particular need and vulnerable to distress, and who may benefit from earlier and targeted interventions to better support their illness understanding.

## **Limitations**

This study has some limitations. First it was an evaluation of routine service provision and therefore was a naturalistic uncontrolled design and limits generalisability to other carer populations and settings. Though changes in illness beliefs were attributed to the active intervention, it is also possible the findings could be due to other factors not previously identified or measured. The group format may have driven the positive changes observed. Further, whilst no substantial differences were observed between carers who provided complete pre and post data and those who did not, it is possible that the former may have had a more positive stance towards the group and its aims and greater readiness to modify their beliefs in the context of new information. The cross-sectional design also precludes definitive conclusions being offered about the directionality of the findings and to what degree changes in carer beliefs would have changed naturally in the absence of the intervention. The results, however, are in line with the pattern of previous findings.<sup>29, 32</sup> A second limitation reflects the absence of follow up data and an assessment of the relevance and implications of belief change for other aspects of carer and patient behaviour and functioning. For example, it is unclear whether changes in carer beliefs impact on illness course and patient relapse. It is also unclear whether an improved understanding of psychosis impacts the quality of the caregiving relationship. Identifying possible mechanisms of change could support more targeted workshops. Since we already have some evidence detailing how carer distress and negative caregiving appraisal can persist<sup>15, 24</sup> the absence of follow up

data precluded any conclusions about longer-term outcomes and durability of the initial positive gains. Future studies exploring the durability of belief improvement are indicated. Moreover, future studies should seek to replicate the intervention findings using a controlled design. A third limitation relates to the illness beliefs under measure and the overall bio-psycho-social conceptualisation of psychosis suggested. The model, whilst representing best knowledge and practice, remains embedded with western psychiatry and not necessarily at one with other illness perspectives that may also be considered to play an important role in some BAME groups and cultures.<sup>39, 48-49</sup> Further, exploring the contribution of ethnic membership on specific carer outcomes would be an important area to explore. Future studies should seek to employ qualitative methods to elicit feedback from carers about their experiences of participating. Though there was heterogeneity in the ethnic background of the sample, most carers were female and the parents of the service user. Whilst this reflects a common clinical picture of caring at FEP<sup>13</sup> the generalisability of the current findings to other types of caregiving relationships (e.g. spousal relationships, siblings) cannot be assumed.

## **Conclusions**

Psychosis carers have information needs that include how to best understand and make sense of the illness. Schizophrenia spectrum conditions tend to typically attract lots of negative commentary, stigma, myths and inaccuracies and this is evident from different sources.<sup>50</sup> A brief psychoeducation group intervention for carers that is cognitively based and when delivered as part of routine service provision, might offer an effective approach to improving FEP carers' understanding of their relative's psychosis soon after their first illness onset. Further studies are required to replicate findings and assess longer-term and economic impact.

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